

Research Paper

# National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities

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## Abstract

**Background:** People with disabilities experience worse health and poorer access to health care compared to people without disability. Large-scale health surveillance efforts have largely excluded adults with intellectual and developmental disability. This study expands knowledge of health status, health risks and preventative health care in a representative US sample comparing the health of adults with no disability to adults with intellectual and developmental disability and to adults with other types of disability.

**Objectives:** The purposes of this study were (1) to identify disparities between adults with intellectual and developmental disability and adults with no disability and (2) compare this pattern of disparities to the pattern between adults with other types of disability and adults without disability.

**Methods:** This study compares health status, health risks and preventative health care in a national sample across three groups of adults: No Disability, Disability, and Intellectual and Developmental Disability. Data sources were the 2010 Behavior Risk Factor Surveillance Survey and the National Core Indicators Consumer Survey.

**Results:** Adults with disability and with intellectual and developmental disability were more likely to report being in poor health compared to adults without disability. Disability and intellectual and developmental disability conferred unique health risks and health care utilization patterns.

**Conclusions:** Significant disparities in health and health care utilization were found for adults with disability and developmental disability relative to adults without disability. Disability training for health care providers and health promotion research that identifies disability as a demographic group is needed. © 2015 Elsevier Inc. All rights reserved.

*Keywords:* Developmental disability; Disability; Health surveillance; Disparity

People with disability experience worse health and poorer access to health care than the general population. Health inequity has been defined as differences that are not only unnecessary and avoidable but are also considered unfair and unjust.<sup>1,2</sup> People with disability experience inequities in many aspects of health and health care. The inclusion of disability items on major health surveillance protocols such as the Behavior Risk Factor Surveillance Survey opened an entire disability and health field whereby disparities in health outcomes and access to health care are addressed. This study compares the health of adults with

no disability to adults with intellectual and developmental disability (IDD) and to adults with other types of disability in a representative US sample.

People with disability are vulnerable to high rates of health risks including physical inactivity,<sup>3</sup> obesity,<sup>4,5</sup> smoking,<sup>6</sup> and inadequate emotional support.<sup>7</sup> They also experience high rates of chronic health conditions including diabetes,<sup>8</sup> high blood pressure, arthritis, chronic pain, and heart disease.<sup>7</sup> In addition, this population is vulnerable to disability-related health conditions that can be severely detrimental to functioning and quality of life.<sup>9,10</sup> These conditions vary by type of disability and may include pressure ulcers, overuse injuries, dysphagia, and mental health problems.<sup>11,12</sup> This health risk phenomenon has been described as producing a “thinner margin of health” for people with disability.<sup>13</sup>

Despite having a greater need for health care, people with disability have decreased access to needed health care services. Disparities have been found in cancer screenings, oral health, and cholesterol checks.<sup>7,14,15</sup> Disparities in health care access can be attributed to barriers unique to adults with

Source of support and disclaimer: This work was supported in part by the Centers for Disease Control and Prevention Cooperative Agreement Number 5U59DD000931-02. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

Disclosure: We have no financial disclosures or conflicts of interest to disclose.

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disability.<sup>16</sup> These barriers include physical inaccessibility of health care facilities and exam rooms, communication difficulties with health care providers, lack of adequate medical information<sup>17</sup> and lack of knowledge and understanding of disability on the part of health care providers.<sup>18–20</sup>

Less is known about the health of adults with IDD. Large scale, well controlled health surveillance studies of adults with IDD are complicated by the cognitive impairment associated with IDD and the stigma associated with the condition that makes self-identification of disability status unlikely. Although large scale surveillance research is scarce, evidence does suggest that IDD may confer particular health risks, access to care barriers, and negative health outcomes.<sup>21,22</sup> Adults with IDD are more likely to have unhealthy weight,<sup>23,24</sup> epilepsy,<sup>25</sup> mental illness,<sup>26</sup> and overall poor health.<sup>7</sup>

Large clinic-based studies have found that access to routine health care was compromised in adults with more severe intellectual disability and those living in their family home.<sup>27,28</sup> People with IDD have a particular difficulty with transitioning to adult care services<sup>29</sup> and advocating for themselves in health care settings.<sup>30</sup> Disparities in access to health care for adults with IDD include lower rates of blood pressure checks, vision and hearing screens, cholesterol screens, and cancer screens.<sup>31–34</sup> Due to social stigma, lack of provider training, and insurance constraints, people with IDD in the United States may struggle to find health care providers who are able and willing to care for them.<sup>35</sup> In Australia as many as 90% of general practitioners reported that it was more difficult to provide quality care to patients with IDD and 16% stated that they would prefer not to treat people with intellectual disability.<sup>36</sup>

This study expands knowledge of health status, health risks and preventative health care in a national sample across three groups of adults: No Disability, Disability, and Intellectual and Developmental Disability (IDD). Disparities between the No Disability group and each of the two disability groups are highlighted. Overall health status is compared as well as health related risks including measures of tobacco use, obesity, physical activity, and emotional support. Preventive health indicators include physical exam, mammogram, pap test, prostate screening, flu shot, and dental visit.

## Methods

### *Behavior risk factor surveillance system (BRFSS)*

The Behavior Risk Factor Surveillance System (BRFSS) generated the surveillance data for the Disability and No Disability groups in this study. BRFSS is a telephone survey directed by the Centers of Disease Control and Prevention to track health conditions and risk behavior. All 50 states participate in this survey with over 350,000 interviews conducted yearly. For this study, the 2010 data for

all states and territories is reported. In 2010, the BRFSS had two questions used to screen for disability (1) “*Are you limited in any way in any activities because of physical, mental, or emotional problems?*” (2) “*Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?*” If respondents answered yes to either of these two questions, they were assigned to the Disability group. If respondents answered “no” to both questions, they were assigned to the No Disability group. BRFSS data was obtained from the Disability and Health Data System (DHDS), an interactive state-level disability data tool developed by the Centers for Disease Control and Prevention (CDC) to provide data on health and demographic indicators using the Behavioral Risk Factor Surveillance System and data on expenditures, <http://dhds.cdc.gov>.<sup>37</sup>

BRFSS data are routinely weighted to adjust the sample response by sex (male; female), race (white, non-Hispanic; non-white or Hispanic), and age (18–24; 25–34; 35–44; 45–54; ≥65) to match the statewide sex-race-age distribution. This adjusts the sample for non-response or low response among certain demographic groups, such as young white males. The weighting procedure makes the BRFSS data representative of the total population of adults in the United States.

### *National Core Indicators Consumer Survey*

Though national surveys, such as the BRFSS, include disability screener questions, they are unlikely to reach adults with IDD. People with severe intellectual impairments are unlikely to respond to telephone surveys and people with mild limitations living in the community may not self-disclose disability status. For these reasons, alternative methods of gathering information about the health of adults with IDD are necessary. The National Core Indicators (NCI) is a quality assurance protocol developed by the Human Services Research Institute and the National Association of State Directors of Developmental Disabilities Services to evaluate service outcomes. Participants are randomly selected from all adults receiving developmental disability services and may include people with a range of disabilities such as intellectual disability, cerebral palsy, autism spectrum disorder, or epilepsy. The NCI Consumer Survey was used in this study, which collects information from three sources about adults with IDD. First, demographic and medical record information is obtained from case files. Secondly consumers are asked questions in a face-to-face interview where only responses from the consumer are accepted. Finally, in the third section of the survey, the individual with developmental disability and/or his or her caregiver is interviewed; if the individual is unable or unwilling to respond to the final section of the interview, a response from someone who “knows him/her well” is accepted. This approach of using records, self-report, and a third party responder is supported by Lunskey, Emery,

& Benson<sup>30</sup> who found that the most accurate reports of health and health care utilization were obtained when multiple sources were consulted. This study focuses on NCI Consumer Survey health indicators including health status, health risks, and access to preventive health care. National Core Indicators (NCI) database for the survey years 2009–2010 and 2010–2011 were combined for a total sample of 20,395 adults with IDD. This sample includes individuals from 25 states — Alabama, Arizona, Arkansas, California, District of Columbia, Florida, Georgia, Hawaii, Illinois, Kentucky, Louisiana, Maine, Massachusetts, Missouri, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Ohio, Oklahoma, Pennsylvania, South Dakota, Texas, and Washington. Each state selected a random sample of at least 400 adults from the population of all adults receiving state DD services to participate in the NCI Consumer Survey. Because two sample years were combined for this study, it is possible, although unlikely, for a participant to be sampled twice, once in each year. NCI data are unweighted estimates.

Overweight and obesity status was determined from the Body Mass Index, which we computed from the height and weight reported on the case file portion of the NCI. Preventive health care visits were also reported in the case file portion of the NCI. For the vast majority of the health items the BRFSS and the NCI used identical wording and are directly comparable. One exception is emotional support. The BRFSS asked “How often do you get the social and emotional support you need.” A response of “rarely or never” was considered to have inadequate emotional support. This type of wording is unlikely to be understood by people with IDD so proxy questions for emotional support were used. During the face-to-face interview portion of the NCI survey, people were asked several questions regarding relationships in their lives. Inadequate emotional support was constructed from the following two items in

the interview section of the Consumer Survey: “Do you have a best friend?” (If participant had difficulty understanding this question it could be alternatively worded as “someone to talk to about personal things”) and “Do you feel lonely?” If participants responded that they did not have a confidant or often felt lonely, they were considered to have inadequate emotional support.

### Analysis

Differences between groups were compared using the reported confidence intervals. Overlapping confidence intervals indicate that the difference between groups is not significant. Prevalence ratio was calculated by comparing the proportion of people in each group not having received services or experiencing health risks to the comparison group. This statistic does not control for any other demographic variables.

### Results

Data are presented for the No Disability ( $n = 312,144$ ), Disability ( $n = 132,812$ ), and IDD ( $n = 20,395$ ) groups on all measures. The No Disability and Disability group were weighted, and the prevalence of disability reported by the BRFSS for this survey year was 22%. Demographic information is presented in Table 1. The Disability group was slightly older than the other two groups. The percentage of men in the IDD sample was significantly larger than in the other samples. This preponderance of males was expected as developmental disabilities are more common in males than in females.<sup>38</sup> The higher rate of blacks in the IDD sample compared to the other samples is consistent with a recent study finding the prevalence of intellectual disability to be twice as high for black children compared to white or Hispanic children.<sup>39</sup>

Table 1  
Demographic Characteristics of No Disability, Disability, and IDD groups

Characteristic	No Disability <sup>a</sup> ( $n = 312,144$ ) Percent (95% CI)	Disability <sup>a</sup> ( $n = 132,812$ ) Percent (95% CI)	Developmental Disability <sup>b</sup> (IDD) ( $n = 20,395$ ) Percent (95% CI)
Male	38.5 (38.3, 38.7)	36.1 (35.8, 36.4)	56.6 (55.9, 57.3)
White, non-Hispanic	77.4 (77.2, 77.5)	80.0 (79.8, 80.2)	70.9 (70.3, 71.5)
Black, non-Hispanic	8.0 (7.9, 8.1)	8.0 (7.9, 8.1)	19.1 (18.6, 19.6)
Other, non-Hispanic	6.7 (6.6, 6.8)	6.8 (6.7, 6.9)	4.4 (4.1, 4.7)
Hispanic	7.9 (7.8, 8.0)	5.2 (5.1, 5.3)	5.6 (5.3, 5.9)
Age range			
18–34	28.7 (28.5, 28.9)	12.2 (12.0, 12.4)	32.3 (31.7, 32.9)
35–54	41.9 (41.7, 42.1)	43.1 (42.8, 43.4)	45.2 (44.5, 45.9)
55+	29.4 (29.2, 29.6)	44.7 (44.4, 45.0)	22.5 (21.9, 23.1)
Severity of ID ( $n = 17,679$ )			
Mild			35.7 (35.0, 36.4)
Moderate			26.6 (25.9, 27.3)
Severe			15.6 (15.1, 16.1)
Profound			22.1 (21.5, 22.7)

<sup>a</sup> Percentages calculated using weighted data.

<sup>b</sup> Unweighted.

Table 2  
Health Risk Behaviors across No Disability, Disability, and IDD groups

	No Disability <sup>a</sup> (n = 312,144)	Disability <sup>a</sup> (n = 132,812)	PR	Developmental Disability (IDD) <sup>b</sup> (n = 20,395)	
	Percent (95% CI)	Percent (95% CI)		Percent (95% CI)	PR
Smokes	15.2 (14.9, 15.5)	26.7* (26, 27.4)	1.7	7.0* (6.6, 7.4)	.46
Overweight	37.1 (36.8, 37.4)	31.7* (31, 32.4)	.85	29.2* (28.6, 29.8)	.78
Obese	23.8 (23.5, 24.1)	38.2* (37.6, 39)	1.6	31.1* (30.5, 31.7)	1.3
No physical activity in past month (2009 BRFSS) <sup>c</sup>	10.0 (9.7, 10.3)	22.0* (21.3, 22.7)	2.2	45.1* (44.4, 45.8)	4.5
Inadequate emotional support <sup>d</sup>	7.2 (7, 7.4)	12.1* (11.6, 12.6)	1.7	31.6* (31.0, 32.2)	4.4

\**p* < .05.

<sup>a</sup> Percentages calculated using weighted data.

<sup>b</sup> Unweighted.

<sup>c</sup> Physical activity was not included on the 2010 BRFSS, 2009 data are reported.

<sup>d</sup> On the NCI, inadequate emotional support was defined as no one to talk with about personal things and feels lonely.

### Health risks

#### Tobacco use

As shown in Table 2, nearly 27% of the Disability group reported smoking cigarettes, making them 1.7 times more likely to smoke than adults without disability. In contrast, the IDD group was much less likely to smoke compared to the other two groups.

#### Overweight/obesity

Adults in the Disability group were slightly less likely to be Overweight but significantly more likely to be Obese (PR = 1.6) compared to the No Disability group. The IDD group was 1.3 times more likely to be Obese compared to the No Disability group.

#### Physical inactivity

Adults in the Disability group were more than twice as likely to have had no exercise in the past month; the risk of physical inactivity in the IDD group was 4.5 times higher than the No Disability group.

#### Inadequate emotional support

Adults in the Disability and IDD groups were significantly more likely to lack emotional support with a prevalence ratio of 1.7 and 4.4, respectively. 11.9% of adults with IDD reported often feeling lonely and 23% reported that they did not have a best friend or someone to talk to about personal things.

#### Health status

As shown in Table 3, poor overall health was reported for approximately 1% of adults in the No Disability group compared to 14% of the Disability group, which reflects a significant disparity of 12.9. Approximately 5% of adults with IDD reported poor health, which is significantly poorer than the No Disability group.

#### Preventive health care

##### Physical exam

As shown in Table 3, the Disability group and the IDD group were more likely to have received a physical exam in the past year.

Table 3  
Health Status and Preventive Health Care across No Disability, Disability, and IDD groups

	No Disability <sup>a</sup> (n = 312,144)	Disability <sup>a</sup> (n = 132,812)	PR	Developmental Disability (IDD) <sup>b</sup> (n = 20,395)	
	Percent (95% CI)	Percent (95% CI)		Percent (95% CI)	PR
Reported poor overall health	1.1 (1, 1.2)	14.0* (13.5, 14.5)	12.7	5.1* (4.8, 5.4)	4.6
No physical exam in past year	33.2 (32.9, 33.5)	32.0* (31.2, 32.8)	.96	13.8* (13.3, 14.3)	.42
No flu shot in past year	61.3 (61, 61.6)	57.3* (56.7, 58)	.94	42.7* (42.0, 43.4)	.65
No dentist visit in past year	29.6 (29.3, 29.9)	40.8* (40, 41.6)	1.4	28.7* (28.1, 29.3)	.97
No PSA test in past 2 years (men 50+)	30.7 <sup>c</sup> (30.1, 31.3)	32.1 <sup>d</sup> (31.2, 33)	1.0	56.3* (54.7, 57.9)	1.8
No Pap test in past 3 years (women over 21) <sup>d</sup>	17.7 <sup>c</sup> (17.3, 18.1)	21.7* <sup>e,f</sup> (20.9, 22.5)	1.2	49.8* (48.8, 50.8)	2.8
No mammogram in past 2 years (women over 40) <sup>e</sup>	23.4 <sup>g</sup> (23, 23.8)	29.3* <sup>h</sup> (28.6, 30)	1.3	43.4* (42.1, 44.7)	1.9

\**p* < .05.

<sup>a</sup> Percentages based on weighted data.

<sup>b</sup> Unweighted.

<sup>c</sup> *n* = 35,055.

<sup>d</sup> *n* = 103,081.

<sup>e</sup> *n* = 46,783.

<sup>f</sup> *n* = 135,665.

<sup>g</sup> *n* = 75,741.

<sup>h</sup> *n* = 147,583.

### *Cervical and breast cancer screening*

Women with IDD were much (2.8 times) less likely to receive a pap test in the past 3 years as were women with disability. Women over 40 in the Disability group and in the IDD group were less likely to have had a mammogram in the past two years (prevalence ratio = 1.3 and 1.9, respectively).

### *Prostate cancer screening*

There were no significant differences in the rate of prostate screening (PSA test) in men over 50 among the No Disability and Disability groups. Men in the IDD group were significantly less likely to have received a PSA test.

### *Flu shot*

Seasonal influenza vaccine is strongly recommended for people with disability by the Center for Disease Control and Prevention. These data suggest that, compared to the No Disability group, people with disability and people with IDD were more likely to have had a flu shot in the past year.

### *Dental care*

The Disability group was 1.4 times less likely to have seen a dentist in the past year. Surprisingly, the IDD group was more likely to have seen a dentist compared to the No Disability group. This is interesting given the research finding that people with IDD have higher incidents of dental problems and overall poor oral hygiene.<sup>40</sup>

## **Discussion**

These findings indicate that people with disability, including IDD, are more likely to have health risks compared to people without disability. Most striking were the differences between the groups in the areas of physical activity and emotional support. Both Disability groups reported less exercise compared to the No Disability group and almost 50% of the IDD sample reported no physical activity *whatsoever* in the past month. People with disability were much more likely to smoke cigarettes (PR = 1.7) as found in previous research.<sup>41</sup> Adults with IDD were less likely to smoke, perhaps due to limited opportunity and choice. Disability and, to a lesser extent, IDD conferred a higher risk of obesity. Physical inactivity was a significant concern for adults with disability (PR = 2.2) and, surprisingly, more of a concern for adults with IDD who were 4.5 times more likely to be sedentary compared to adults without disability. Finally, people with disability were 1.7 times more likely to report inadequate emotional support. For adults with IDD, the situation is especially startling with over 30% of the IDD group reporting inadequate emotional support, a prevalence ratio of 4.4 compared to the No Disability group. It should be noted that the questions used to determine emotional support were certainly not all encompassing and caution should be used in

applying these results to all people with IDD. Given the nature of the survey question, we are also unable to identify the nature of the problem. While social isolation presents a particular concern for adults with IDD who may lack the skills or freedom to independently expand their social network, further research is needed to understand the implications of this finding.

Given the high rate of health risks among people with disability and IDD found in this study and the known association between health risk, health outcomes, and quality of life, effort should be directed toward promoting the health of people with disability. For people without disability, there has been a concentrated effort to improve the health and wellbeing of the population through health promotion programs. Such programs could address the disparate health risks found in this study including obesity, physical inactivity, and inadequate social support. Unfortunately, health promotion interventions that are accessible and appropriate for people with disability are lacking.<sup>42,43</sup> Helpful guidelines have been established for implementing community-based health promotion programs that are inclusive of people with disability.<sup>44</sup> Effective health promotion programs have been developed for adults with mobility limitations<sup>45,46</sup> and for adults with IDD.<sup>47–50</sup> On the other hand, efforts have been made to include adults with disability in mainstream health promotion programs, such as the Chronic Disease Self Management Program.<sup>51,52</sup> One critical element of successful health promotion programs for adults with disability, especially adults with IDD, is involving family members and other caregivers in the program.<sup>53</sup> Determining the long term benefits for people with disability in wellness and prevention programs depends on studies with measured outcomes delimited by demographic group, including disability. Future research is needed to evaluate the benefits for people with disability of health promotion programs that were not explicitly designed for them and to determine when disability-specific programs are more effective.

We found that adults with disability experience decreased utilization of certain health services. Although people with disability accessed primary care services (e.g., physical exam, flu shot, PSA test) at a similar rate to people without disability, they were less likely to have regular dental visits. Though people with IDD were equally likely to have received primary care and dental care services, it was striking that the IDD group was significantly less likely to receive a PSA test and that both the disability and IDD groups were significantly less likely to be referred for specialized services such as Pap test and mammogram. These results are comparable to the Havercamp et al<sup>7</sup> study that used a similar methodology in North Carolina as well as other studies indicating that health risks and access to health care for people with disability are a pervasive problem in the United States.<sup>54,55</sup> Although this study did not explore the reasons for this utilization pattern, other researchers have pointed to physicians' misperceptions

of the risk of cancer related to the assumption of asexuality<sup>56</sup> as well as attitudes and knowledge about the life expectancy and quality of life of people with disability.<sup>57</sup> Another issue that may limit utilization of cervical and breast cancer screening is that women with IDD have limited knowledge about cancer screenings and may need support to overcome any anxiety or reluctance associated with these screenings.

This study demonstrated clear inequities in health access for people with disability. Growing research evidence points to the absence of professional training on disability for health care practitioners as being one of the most significant barriers preventing people with disability from receiving appropriate and effective health care.<sup>20,58,59</sup> As noted in the World Report on Disability,<sup>60</sup> negative experiences with the health care system, such as experiencing disrespect, insensitivity, and devaluation, may lead persons with disability to eschew seeking care and rely upon self-diagnosis and treatment. Physicians lack the expertise and skills to distinguish clinical concerns arising from disability from those related to other health conditions; and limited knowledge and understanding of disability deleteriously affect quality of care, contributing to delays in diagnosis and treatment, unsafe care, and inequities in care.<sup>61,62</sup> Few professional health care training programs address disability issues in their curricula.<sup>53,55,60,63–69</sup> We submit that a core curriculum element on disability competency should be a requirement for accreditation or receipt of Federal funding for professional training of physicians, nurses, and allied health providers. This training should be provided at the preservice level and as continuing education for health care providers. In addition, applicants who seek either a medical or other professional health care license should be required to demonstrate disability competency.

Our study examined the health, health risks, and access to health care for adults with disability and adults with IDD compared to adults without disability. This study design afforded a unique insight into the health and health care of adults with IDD and revealed that this group is very similar to adults with disability in terms of health disparities. This finding is important in that it draws attention to health concerns among people with IDD. Without disability-specific health surveillance information, leaders and policy-makers may assume that the comprehensive services and supports that are provided through the DD service system assure good health and good access to health care. While health promotion programs, as previously discussed, may be a good solution for adults with disability and IDD alike, additional supports to promote healthy living and participation as an active partner in health care may be available and appropriate for adults with IDD. For example, people who receive IDD services have a service plan that describes goals and activities and that is reviewed annually by the individual and his or her care team. While these plans commonly address safety,

healthy choices such as eating and physical activity are rarely addressed. Including health education and health promotion goals in the individual service plan could substantially improve the health and active participation in health care of adults with IDD.

## Limitations

This study was limited by the survey methodology, which prevented us from confirming disability status, exploring the nature or severity of disability, or checking the accuracy of the information reported. The NCI data for the IDD group was limited to adults receiving state DD services; these findings may not generalize to the many adults in the community who may have an intellectual or developmental disability but do not receive services. The BRFSS identifies people with disability using two screener questions. This method has been questioned for its accuracy especially compared to other national surveys such as the American Communities Survey (ACS) and the National Health Interview Survey (NHIS) both of which have six disability screening questions. Given that the prevalence of disability in this sample was higher than the prevalence cited by other sources such as the Census Bureau it is possible that the BRFSS is over identifying disability status and caution should be used in the application of these results for any specific disability type. Research examining the validity of the BRFSS questions has suggested that BRFSS questions may be less accurate for people with transient conditions, mental illness, and sensory disorders.<sup>70</sup> In addition, there have been some concerns regarding the representativeness of the BRFSS given the decreased use of landlines in the United States (BRFSS began including cell phone numbers in 2012) though recent research comparing health outcomes on the BRFSS to other national surveys indicated similar results.<sup>71</sup> Though this study demonstrates disparities between adults with and without disability; prospective longitudinal research is needed to better understand the patterns of disparities affecting people with different types and degrees of disability.

## Conclusions

The use of large scale nationally representative survey data gives a unique look into the health access and health behaviors of Americans with disability. This study demonstrated the gaps in health care access at a national level, particularly for people with IDD, and shed light on the areas where intervention and reform are most needed. Similarly, this study provides valuable knowledge of the health risks of people with disability and IDD and can help direct practice and policy. Studies such as this also provide benchmarks from which to measure change over time and after systemic changes.

## Acknowledgments

The authors would like to express our gratitude to Brian S. Armour, PhD, Economist, and Alissa Cyrus Stevens, MPH, CPH, Health Scientist, National Center on Birth Defects and Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia for help with BRFSS data.

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